

MOAIDD

**Missouri Alliance for Individuals
with Developmental Disabilities**

Annual Report

2002-2003

**Department of Mental Health
Division of Mental Retardation and Developmental Disabilities**



Introduction

The Missouri Alliance for Individuals with Developmental Disabilities (MOAIDD) is a statewide volunteer organization consisting of individuals with developmental disabilities and family members of individuals with developmental disabilities. MOAIDD operates under State regulation 9 CSR 45-5.04. To read the regulation go to website:

<http://www.sos.state.mo.us/adrules/csr/current/9csr/9c45-5.pdf>

The purpose of MOAIDD is to visit Missouri citizens with developmental disabilities and make recommendations to improve the quality of their lives. MOAIDD fulfills this purpose by conducting periodic visits to individuals in their homes who are receiving Home and Community Based Waiver residential services through Missouri's Department of Mental Health, Division of Mental Retardation & Developmental Disabilities (MRDD).

MOAIDD volunteers conduct visits at the convenience of the person and only with his/her permission and/or the legal guardian's permission. Throughout the process, the focus is on the individual and his/her rights, dignity, and quality of life. The visits are accomplished by a team of volunteer consumers and family members who have been trained to observe and report objectively what they see in the daily life of the individual. Through visits, the volunteers will provide information for the visit report that the Division shares with the individual visited and his/her guardian, the provider of services and the applicable Division of MR/DD regional center.

Visits are guided by procedures for observation and interview that ensure the consistent gathering of useful data for enhancing the life of the individual visited. Volunteers do not evaluate service programs according to local, state or federal regulations, but instead try to determine if individuals are leading as full a life as possible.

MOAIDD VISION

MOAIDD believes that all Missourians of diverse backgrounds and abilities will be fully integrated into all aspects of society: culturally, economically, politically and socially. This vision will be evidenced when people have:

Choices in living, working and recreating (including home ownership and vacations);

Friends in the community;

The opportunity to help and give to others;

The services and/or supports that they need and want;

Free access to all aspects of community life, total inclusion in schools and opportunities that really support people;

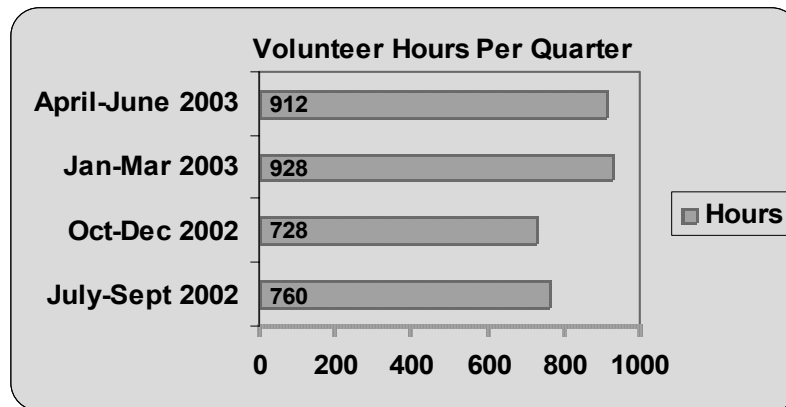
Adequate resources;

The opportunity to be in charge and really direct their support services, acceptance and understanding from the community.



Volunteer Contribution

The MOAIDD Program has 145 active volunteers. During fiscal year 2003, MOAIDD staff and team leaders trained thirty-seven (37) new volunteers. In addition, volunteers contributed over 3,328 hours at an estimated financial value of \$66,560.00*. Volunteer contributions include conducting visits, attending board meetings, representing the Division on workgroups and providing training and technical assistance to new volunteers. Volunteers donate, on average, eight hours per visit. From July 1 2002 – June 30, 2003 volunteers visited 116 individuals supported by over 110 agencies.



*Volunteer estimated wage value is \$ 20.00 per hour. The wage value is the average hourly wage of a Licensure and Certification Surveyor. (Program Specialist II)



Visit Results and Common Themes

Volunteers look at Quality of Life in the areas listed below and make recommendations that are intended to enhance the quality of the individual's life. Volunteers made a total of **584** recommendations in the following areas:

⇒ **Red and Yellow Flags:** Flags are areas that jeopardize the health and welfare of the individual including suspected abuse/neglect. Flags are immediately addressed by the regional center and provider.

There were **no** Red flags and a total of **15** Yellow flags identified with the following themes:

- Home is unsafe and not clean
- No evidence of fire fighting equipment, evacuation plan and operable smoke detectors
- Individuals are unable to communicate due to broken adaptive devices or staff not knowing sign language



Visit Results and Common Themes

- ⇒ **Overriding Concerns:** Areas that may not result in immediate danger to the individual but are of enough concern that they must be addressed.

A total of **11** Overriding Concerns identified with the following themes:

- Medical issues: no current physical examinations, individuals on numerous medications with and possible side effects.
- Individuals not engaged in meaningful activities
- Individuals not receiving training in skills to increase independence

- ⇒ **Regard for the Individual:** Volunteers look at activities that respect and promote the dignity of individuals, and promote involvement in the community. This includes individuals having control over their lives, relationships that are supported and encouraged, a variety of leisure opportunities, enjoyment of their home and dreams and goals.

A total of **217** recommendations were made with the following themes:

- Individuals need opportunities to develop community interests, relationships, connections and join community or advocacy groups
- Individuals need opportunities and support to visit and stay connected with their families
- Individuals need opportunities for privacy in their homes and to be treated as adults

- ⇒ **Personal Growth:** Volunteers look at activities that promote personal growth for the individual. This includes opportunities to increase personal independence, develop personal relationships, make daily choices, and express spirituality and sexuality.

A total of **129** recommendations were made with the following common themes:

- Develop agency sexuality policies and sexuality and relationship training for individuals supported and staff
- Increase individuals' communication skills through adaptive devices and sign language
- Provide opportunities for individuals to learn new skills, pursue jobs and relationships



Visit Results and Common Themes

- ⇒ **Staff:** Volunteers observe the skills of staff and the way staff interacts with individuals. This includes the training staff has and if staff are friendly, supportive, open to new suggestions and genuinely seem to like the individuals they are supporting.

A total of **80** recommendations were made with the following common themes:

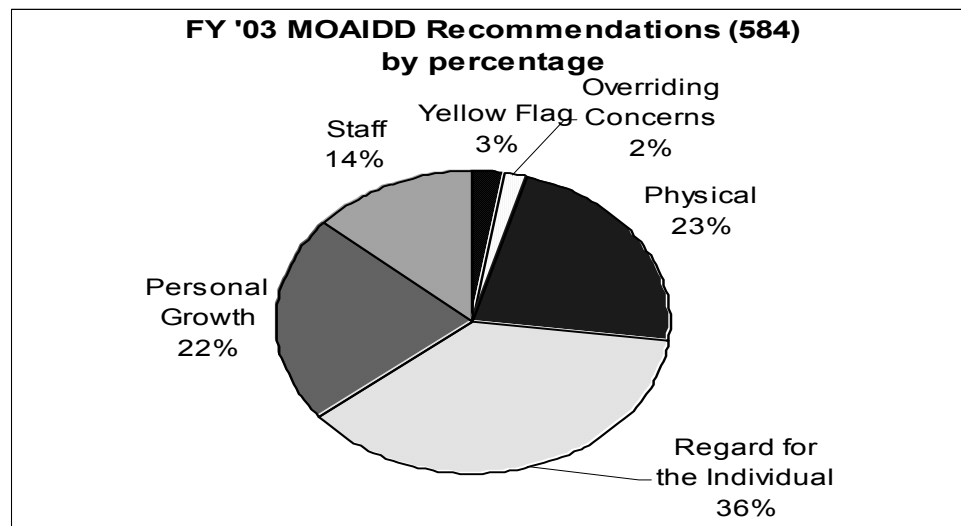
- Provide training for staff in various areas: aging process, sexuality, communication, sign language and positive behavioral support
- Increase communication among staff in order to better support the individual
- Staff need to teach individuals skills to increase their independence such as medication and side effects, life skills, job skills, social skills

- ⇒ **Physical Setting:** Volunteers observe the exterior and interior of the home to determine if the home reflects the individuals who live there, personal space, personalization and any adaptations.

A total of **132** recommendations were made with the following common themes:

- More personalization of the home: display family photos, artwork, collections, plants, gardens
- Complete or make needed repairs: common repairs include carpets, lighting, furniture, walls, driveways and making sure the home is accessible for the individuals
- Develop and practice emergency drills on a routine basis

Illustration of MOAIDD Recommendations





Follow-up to MOAIDD visits

The individual's personal planning team and regional center quality assurance staff reviews all MOAIDD recommendations and submits a written response to all recommendations to the MOAIDD coordinator. Written follow-up was received for 97 of the 116 visits, 19 visits did not require written follow up as no recommendations were made.

Positive things that happened for individuals as a result of a MOAIDD visit:

- Many individuals joined their local People First groups
- Individuals have developed unpaid friendships, inviting friends over to eat, doing community activities together, hosting parties and BBQs
- Individuals have chosen and purchased items to decorate their homes
- Many individuals have participated in Abuse Prevention training
- Individuals have been reconnected with their families through visits, cards and letters
- Individuals are learning new skills to manage their homes such as cooking, cleaning and what to do in the case of an emergency
- Individuals have joined their local YMCA or gym to exercise and develop new relationships
- Several individuals have moved to safer and cleaner homes
- Individuals have received communication evaluations and adaptive equipment to help them communicate with others
- Positive Behavioral Support plans have been developed for individuals to help staff better support them
- Many provider agencies have developed sexuality policies for individuals supported and staff



Program Satisfaction

MOAIDD evaluates program satisfaction through a visit evaluation form that the volunteer team leaves with the person visited and the provider agency.

The Satisfaction evaluation form includes the following questions:

- (1) Was it a good time to visit?
- (2) Were the volunteers courteous and respectful?
- (3) Were the volunteers too personal or inappropriate? The evaluation also asks for:
- (4) Suggestions to improve the visit process
- (5) What was most helpful? And Comments

A total **52** visit evaluation forms were returned for the 116 visits.



Program Satisfaction

⇒ Positive comments include:

- "Volunteers provided helpful resources and information"
- "The interest and concern the volunteers showed the individual and provider is appreciated"
- "By the time they left, I felt like I had two new friends"
- "What a great service, as an agency owner, how wonderful to have so many eyes looking out for our special individuals!"
- "The interest the team showed in the home and the approval of our work"
- "It's nice to know other individuals care about the persons welfare as we do, thanks for caring".
- "I liked that they treated me with respect and spoke kindly to me"
- "Realizing that MOAIDD staff is acting out of interest and concern for our individuals and have a good understanding of their needs"
- "Getting new ideas for the person was very helpful"
- "Your visit was uplifting and a joy!"
- "The visit from the MOAIDD team was great showing great concern for the consumer and also respect for the provider"
- "Just keep sending team members like these, they were very open and friendly and did not have their own agenda"
- "This was a very good team, thanks for visiting with us, we always like to talk and meet new individuals"
- "It can be very difficult to go into individuals' homes, but I felt the team did an excellent job"
- "All of the ladies were nice, I enjoyed all of the attention they gave me"
- "The questions they asked were vital to the persons welfare and thought provoking which gave the person a chance to give his opinion and thoughts"

⇒ Comments on ways to improve the visit process:

- "Interview someone who can answer questions appropriately"
- "Possibly give more information as to the purpose of the visit when making the initial contact as to what the purpose and goals are for the visit."
- "The questions might be worded to be understood easier and more precise and to the point"



MOAIDD Board Accomplishments

The MOAIDD Board has accomplished much this year. Below you will find a list of their accomplishments:

- ⇒ Improved relationships with Regional Centers and Providers: that has resulted in more receptive, positive and quicker responses to MOAIDD recommendations.
- ⇒ MOAIDD process is more efficient, better data collection methods for volunteers, staff and Regional Centers.
- ⇒ MOAIDD is more person-centered, one example is that a young woman who received a MOAIDD visit has recently become a MOAIDD volunteer.
- ⇒ Newly created MOAIDD website and newsletters.
<http://www.dmh.mo.gov/mrdd/moaidd/index.htm>
- ⇒ MOAIDD has made a difference one person at a time; one example is that a gentleman moved to a new apartment after a MOAIDD visit.
- ⇒ Volunteer training has been revised and because of good training volunteers are making good quality of life improvement recommendations.
- ⇒ We have trained many new volunteers who are doing visits. (37 new volunteers)
- ⇒ The board has nearly full membership and has board members that are interested, committed and also volunteers. (7 new Board members)
- ⇒ We have made many more visits this year. (88% increase from last fiscal year)
- ⇒ Improved data collection and reporting; that has enabled the people who make decisions to make informed decisions.
- ⇒ MOAIDD now has full trained staff, the regions and districts are working together with the staff & volunteers.
- ⇒ We have many more long-term committed volunteers who make a difference when visiting people.
- ⇒ Revisited the constitution and by-laws. (Amended Article IV, Section VII)
- ⇒ MOAIDD has good committed staff to support it.
- ⇒ The board and staff are a good team.
- ⇒ MOAIDD published its first annual report.



Recommendations For System Improvement

Based on the MOAIDD visits completed this Fiscal Year, MOAIDD recommends the Division consider the following recommendations:

1. Provide training and technical assistance to providers and Regional Center staff on creating real home environments. A common theme reported by volunteers is that the homes are safe and for the most part clean. However the homes are also sterile and do not feel like real homes.
2. Adopt through Division policy the Missouri Quality Outcomes.
3. Require that every provider have a policy on sexuality and mandatory training on sexuality. This would include sexuality training for staff and the consumers supported. MOAIDD will be further exploring this topic in the upcoming year.



MOAIDD Board and Staff

The MOAIDD Board is comprised of persons with developmental disabilities and family members. There is a member from each of the eleven regions and four At Large members. Below are the Fiscal Year 2003 Board members and program staff:

MOAIDD Board Officers and Members

Gary Stevens, Chair	Rolla, MO	Lawrence Lueckenhoff	Jefferson City, MO
Sharon Courter, Vice Chair	St. Joseph, MO	Tony Miller	Morrisville, MO
Mamie Benson, Secretary	Kennett, MO	Clarice Woodard	St. Louis, MO
Karen Allan	Jefferson City, MO	Joe Wrinkle	Kansas City, MO
Evelyn Austin	St. Louis, MO		
George Boyle, Ex officio	Columbia, MO		
Juanita Carroll	Marshall, MO		
Tim Graybill	Joplin, MO		
Jean Hellwege	Cape Girardeau, MO		
Jo Hodges	Blue Springs, MO		

MOAIDD Staff

Anne Jackson, State Coordinator
 Tequias Bass, Coordinator – East
 Shelly Brown, Coordinator – North
 Chad Courter, Coordinator – Central
 Teri Wondra, Coordinator – South
 Glenna Herod, Support Staff